



Open Access Repository
www.ssoar.info

"I Am Human Too!" 'Probeerruimte' as Liminal Spaces in Search of Recognition

MacLeod Budge, Fiona; Wels, Harry

Veröffentlichungsversion / Published Version

Zeitschriftenartikel / journal article

Empfohlene Zitierung / Suggested Citation:

MacLeod Budge, F., & Wels, H. (2016). "I Am Human Too!" 'Probeerruimte' as Liminal Spaces in Search of Recognition. *Social Inclusion*, 4(4), 140-149. <https://doi.org/10.17645/si.v4i4.701>

Nutzungsbedingungen:

Dieser Text wird unter einer CC BY Lizenz (Namensnennung) zur Verfügung gestellt. Nähere Auskünfte zu den CC-Lizenzen finden Sie hier:
<https://creativecommons.org/licenses/by/4.0/deed.de>

Terms of use:

This document is made available under a CC BY Licence (Attribution). For more Information see:
<https://creativecommons.org/licenses/by/4.0>

Article

“I Am Human Too!” ‘*Probeerruimte*’ as Liminal Spaces in Search of Recognition

Fiona MacLeod Budge ^{1,*} and Harry Wels ^{2,3,4}

¹ To-The-Point Consultancy, 2042KP Zandvoort, The Netherlands; E-Mail: ttpconsultancy@yahoo.co.nz

² Faculty of Social Sciences, Vrije Universiteit Amsterdam, 1081 HV Amsterdam, The Netherlands; E-Mail: h.wels@vu.nl

³ African Studies Centre Leiden, Leiden University, 2333 AK Leiden, The Netherlands; E-Mail: h.wels@ascleiden.nl

⁴ Department of Geography and Environmental Studies, University of the Western Cape, Bellville, 7535, South Africa

* Corresponding author

Submitted: 21 June 2016 | Accepted: 30 August 2016 | Published: 10 November 2016

Abstract

This paper explores the Dutch concept ‘*probeerruimte*’¹ in relation to the statement ‘human as a contested concept’, a highly relevant topic in disability studies. *Probeerruimte* encompasses the idea that people need space to ‘try things out’, a liminal space that facilitates personal development. It was conceived in a context where institutional practices exerted restrictive control over the lives of people with learning difficulties, denying them rights to self-determination and personal growth, rights that are integral to experiences of ‘being human’. The concept emerged about 20 years ago, and was revived during two studies conducted in 2014 and 2015. The studies, commissioned by Disability Studies in Nederland (DSiN), explored perceptions of social inclusion. Study findings reveal the significance of associated concepts, inclusive of connectivity, citizenship, liminal spaces, and ‘risk taking’. Of critical importance is the need to challenge hegemonic practices that all too often disempower people with learning difficulties, remove their rights and, relegate their status to below citizenship. This paper addresses the relevance of *probeerruimte* for people with learning difficulties, from their perspectives, and examines how institutions can facilitate this process. Opinions from ‘all people’ involved in the conversation are used as data so as not to ‘label’ or make too strict a distinction between people with or without learning difficulties. The authors affirm the need to create *probeerruimte* to facilitate varied ways of existing. Ideally these ways of existing will promote opportunities for people with learning difficulties to engage in meaningful spaces, affirm their rights to citizenship and recognise their humanity.

Keywords

citizenship; disability; learning difficulties; *probeerruimte*

Issue

This article is part of the issue “Humanity as a Contested Concept: Relations between Disability and ‘Being Human’”, edited by Paul van Trigt (Leiden University, The Netherlands), Alice Schippers (Disability Studies in Nederland, The Netherlands) and Jacqueline Kool (Disability Studies in Nederland, The Netherlands).

© 2016 by the authors; licensee Cogitatio (Lisbon, Portugal). This article is licensed under a Creative Commons Attribution 4.0 International License (CC BY).

1. Introduction

This article explores the concept ‘*probeerruimte*’ (the literal translation of this Dutch word is ‘trying space’) in relation to the theme “human as a contested concept”. The

contested nature of humanness is perhaps no more relevant than in studies related to ‘cognitive disability’ (Goodley & Runswick-Cole, 2016; Goodley, Runswick-Cole & Liddiard, 2015; Kittay & Carlson, 2010). The ‘disability’ lens facilitates a critical look at what it means to be hu-

¹ *Probeerruimte* is not a regular word in Dutch language and cannot be found in a Dutch dictionary. It is however, cited regularly in Dutch literature related to Health and Development. It is pronounced ‘pro-beer-row (as in rhyming with ‘cow’) mte’.

man, both in terms of honouring our humanness and in recognising how disconcerting our humanness can be (Goodley, Lawthom, & Runswick-Cole, 2014). Confrontations with cognitive disability challenge our perceptions of what it means to be human, as philosophical conceptions of humanness are predominantly determined by the ability to reason. Inherent to disability are notions of 'restriction' in various domains, including restrictions in expressing rationality, taking risks, and having opportunities to try things out. *Probeerruimte*, as the literal translation implies, centres on creating space to try things out. Significant to recognise here are multiple meanings of 'space,' inclusive of physical and psychological space to develop interactions and/or a space between people. *Probeerruimte* has connotations with "*geographies of disabilities*" as described by Hall and Kearns, in terms of "opening space" (2001, p. 237). It encompasses the notion that people should be given space to 'try things' necessary for personal development and growth. Implicit to trying things, however, is the 'taking of risks' and recognising the formative impacts this has on experiences of being human. Risks entail opening, negotiating and even losing our space to others, in the endeavours people make to be recognised as human. Often persons with intellectual, psychological or physical restrictions are denied this space which at times elicits the protest "We are human too!!" This protest was echoed in interviews, among people labelled as having 'learning difficulties', in recent studies commissioned by Disability Studies in Nederland (DSiN). Findings from these studies contribute to our exploration of the term *probeerruimte* and its relevance for the statement "human as a contested concept" (cf. Bourke, 2013). It is beyond the scope of this paper to discuss a wide range of disabilities, so discussion is restricted to people labelled as having moderate to mild learning difficulties.

The article is structured as follows: the background provides a short description of research contributing to this paper. This is followed by an explanation of *probeerruimte* and an account of the positive and negative associations with the literal translation of *probeerruimte*. After this comes a discussion about the closely related concepts 'space and place' and 'risk taking'. Next is a brief discussion of the significance of *probeerruimte* for people with learning difficulties and their perceptions of what it means to be human. Before the conclusion, there is a short discussion about the need to challenge hegemonic practices that serve to perpetuate the ways in which being human is contested. The paper concludes with reflections on the central concepts that emerged in the studies.

2. Background

Two research projects, commissioned by DSiN, were conducted in 2014 and 2015 to explore perceptions of in-

clusion and participation, primarily among people with learning difficulties living in The Netherlands. The first project evaluated a 'Buddy Project', designed and implemented by DSiN, that aimed to increase meaningful participation of disabled people in a disability conference in held in Amsterdam at the end of 2013 (Budge, Schippers, Kool, Miranda-Galarza & Van Hove, 2016). The second project explored perceptions in regard to inclusive and collaborative research and programme development, specifically in relation to the development of a National Disability Programme (NPG) (Budge, Ebben, & Van Hove, 2015). Although the projects were based in The Netherlands, some participants involved in the research lived outside of The Netherlands.

DSiN has been working towards ensuring the full and meaningful inclusion of people with disabilities in the development of a National Disability Programme. These efforts involve the notion of 'trying a new space' as people with learning difficulties are encouraged to engage in spheres such as programme design and development and decision making situations, which are usually dominated by people without learning difficulties. In these two studies a total of 31, individual and paired², semi-structured interviews (cf. Green & Thorogood, 2013) were conducted; six were with people with learning difficulties. In addition, six focus group interviews (cf. Rabiee, 2004) were held that engaged 12 participants with learning difficulties. During the second research project *probeerruimte* emerged as a concept needing more exploration in disability research. To support this demand, further interviews were conducted to gather more information. Two more focus group interviews, involving seven people with learning difficulties, and five individual interviews with people without learning difficulties, who are closely involved in the disability arena, were conducted. DSiN is a relatively small and cohesive disability group. Participants in these studies were people with whom DSiN has an ongoing dialogue. All participants willingly agreed to participate.

3. *Probeerruimte*

The term *probeerruimte* emerged around 20 years ago, and was coined by the Dutch developmental psychologist Willem De Ruiter following a visit he and some colleagues made to the US with the aim of learning what was happening for people with learning difficulties. In the US, they witnessed a close alignment between efforts by people with disabilities for inclusiveness, and the civil rights movement. Coinciding with this was an institutional paradigm shift in The Netherlands with mission statements of various organisations claiming the need for 'freedom', 'independence', 'exercise of choice', 'autonomy' and 'inclusion'. This shift was supposed to herald a move toward opening spaces for people with learning difficulties to exercise choice and autonomy. The aim

² The decision to 'pair' some interviews was determined by the need for assistance with communication, both in terms of language, as the primary researcher does not have a good command of the Dutch language, and comprehension.

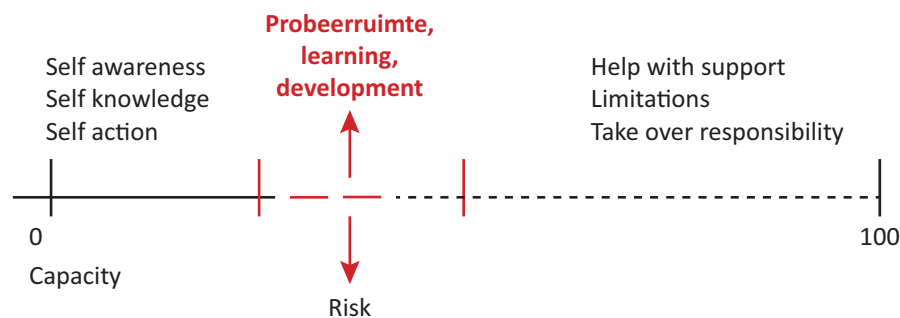


Figure 1. Learning, development and risk. Source: Personal communication (De Ruiter, 24 February 2016).

was to encourage freedom from restrictive institutions where people lived in conditions of tight control and coercion (Smit, 2012). Prior to this shift people with learning difficulties, living in such institutions, were not accorded the same civil rights as other citizens (European Intellectual Disability Research Network, 2003).

A close look at the current situation of people with learning difficulties in The Netherlands shows that the impact of this ‘shift’ has been variable. Despite the ‘good’ intentions, shifts toward independence, freedom, and exercise of choice, has occurred more for people with physical or sensory impairments than for people with learning difficulties and mental health needs. The latter groups still mostly live in institutionalised settings (Schoonheim & Smit, 2007; Townsley, Ward, Abbott, & Williams, 2009). This is possibly related to the resistance of institutional staff working with people with learning difficulties. De Ruiter observed this more than two decades ago. He described how staff reacted with incredulity at this shift and voiced comments such as “the people I work with cannot choose for themselves” (personal communication, 24 February 2016). Staff were concerned that such independence would be too risky and endanger people who were assigned to their care. Thomas (2007), a disability scholar, maintains this ‘concern’ is reflective of a misguided, yet widespread assumption that people with impairment are rendered dependent and as such are in ‘need of care’.

In response to such concerns De Ruiter conceptualized the term *probeerruimte*, linking the term strongly with the notion of ‘personal development’ (personal communication, 24 February 2016). He maintains the term is about creating spaces where people are able to try and do things for themselves, and highlighted the importance of being able to ‘exercise influence’ as prerequisite for human development. Importantly, exerting influence may be over the self as well as others. The following anecdote highlights one of his compelling reasons. A number of years ago, when working with people with learning difficulties, De Ruiter and his colleagues were asked to ‘babysit’ some people who were living in an institution, while the ‘carers’ who usually worked with these people, went out for the evening. De Ruiter and his col-

leagues agreed to this request and were given an extensive and detailed list of what was to happen—who could sit where, next to whom, what and how people would eat, and so forth. De Ruiter felt this was absurd as he was confident the people ‘assigned to his care’ would know perfectly well what the routine would be. The list was put aside and indeed everyone was able to clearly indicate what needed to happen. They were able to exercise their own choice and in doing so demonstrated self-determination.

It was evident the regular staff who sought help with ‘babysitting’ had been exercising regulating power. This scenario resonates with the exercise of bio-power (Foucault, Bertani, Fontana, Ewald, & Macey, 2003), which facilitates an institutionalised form of dependency. People categorised as ‘abnormal’ become recipients of treatment, care and/or welfare as they are compelled to follow institutional norms. Relevant here, is the elaboration of Rose (2007). He describes ‘bio-power’ where authorities intervene in a semi-rationalized way to impinge upon the uniqueness of *human existence*, both at an individual and a collective level.

Consequently, facilitating *probeerruimte* is primarily about ensuring spaces are created where people are able to exercise choice and challenge the restrictive and regulatory practices of ‘professionals’ in the provision of ‘care’. De Ruiter cautions that it is necessary to determine if risks outweigh the benefits when creating space for exercising choice and freedom. The opportunity for net benefit should govern when, where and how much support is needed. It is not a static space but rather a space where boundaries are constantly changing as depicted in the diagram above (Figure 1).

According to Van Hove³, “*probeerruimte*, evokes association with ‘liminal spaces’, ‘borderlands’, ‘margins’, ‘de-territorialisation’ and ‘lines of flight’” (personal communication, 15 December 2015). *Probeerruimte* needs to be a space where trust is engendered and reciprocity is cultivated. It is important to note that efforts to elicit change, in regard to the creation of *probeerruimte*, should be initiated by people with learning difficulties. As Thomas states “the struggles for independent living (or integrated living, as it is sometimes called)

³ Professor Geert van Hove has been professor in Disability Studies and Inclusive Development at the University of Ghent, Belgium, since 1993 and currently is appointed as the Chair of Disability Studies at the VUmc, Department of Medical Humanities, Amsterdam, The Netherlands.

waged by disabled people's movements in the US and the UK, have proved to be much more successful routes to change than attempts to reform professional practice" (2007, p. 99).

4. Negative and Positive Perceptions of the 'Literal' Word *Probeerruimte*

There were both negative and the positive perceptions of the literal word *probeerruimte*, specifically the notion of 'trying', for some of the people with learning difficulties whom we interviewed for this study. In one of the group interviews it was evident that some members bordered on being 'offended' about the literal meaning of the word in relation to their experiences. *Probeerruimte* is not a regular word in Dutch, and for these people it was a 'new' and unrecognisable word. They considered it too 'weak', feeling it did not reflect spaces where their strength and autonomy could be recognised and exerted. The implication of 'trying' was considered almost patronizing, as is evident in the following quotes: "it [*probeerruimte*] doesn't tell me much. If I want something, I don't need a *probeerruimte* for it"⁴; "it doesn't work for me"⁵; "*probeerruimte* is not really a good word"⁶. Better words should refer more to issues like 'connection'⁷, 'meeting'⁸, 'strength development'⁹, 'own strength'¹⁰, 'not client, but a citizen'¹¹. During the discussion, however, it became clear from comments regarding the need for a space where choice and autonomy could be exercised, that their perceptions resonated with the intent of the word as described by De Ruiter. This led to further discussion about how participants would like to express this need. Preferences in the group were for a word that would convey their desire to 'convince' others of their strength and power. In light of this we asked them to consider what the positive aspects of *probeerruimte* could be, as in what spaces are needed for personal growth and self-actualisation? In response, the following ideas were offered:

"It should be meeting space—a place where disabled and non-disabled people can meet." (Jeanette¹²)

Jeanette stressed the importance of 'coaches'¹³ and 'managers' in this encounter, expressing a desire not to parse the distinction between people with 'learning difficulties' and people without 'learning difficulties'.

Expanding on this line of thought, Jeanette, went on to say:

"It is an important space for connecting with others...[where] we can 'share' with others and in doing so raise awareness [about people with learning difficulties]."

Acknowledging the need for personal growth and self-actualisation, another group member contributed the following:

"Efforts towards inclusion need to be 'two ways'... we need to use the UNCRPD to claim our rights." (Harro¹⁴)

Ideas of connectivity and creation of meaningful networks with others were identified as central to how *probeerruimte* should be conceptualised. Meeting others is not enough. It needs to be a space where 'connection' occurs.

Implicit is a demand for appreciation of diversity and diverse ways people have of being in the world (Cockburn, 2007). Frequently, when people with learning difficulties experience difficulty with expression, it is less related to lack of opportunity and more related to obstructed communication. *Probeerruimte* should be a space where obstructions are removed. This idea is supported by the following statements:

"It should be a place where we can think for ourselves." (Henk¹⁵)

"It should be a space where things happen 'with us' and not 'over us.'" (Henk)

"It should be a place of support but not control." (Harro)

Many of the concepts mentioned above resonated with another interviewee, Anneke Wignand, a woman who works with people labelled as 'schizophrenic'. Anneke considers *probeerruimte* central to her work and affirms the idea of it being a place of connectivity. For her the core of *probeerruimte* is:

"To be known and to know people."

⁴ Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'Het [*probeerruimte*] zegt mij weinig. Als ik iets nodig wil, heb ik daar geen *probeerruimte* voor nodig'.

⁵ Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'k Kan er [*probeerruimte*] niks mee'.

⁶ Original quote in Dutch from focus group interview Wolvega, 28 January 2016: '*Probeerruimte* is niet echt het woord'.

⁷ Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'Verbinding'.

⁸ Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'Ontmoeting'.

⁹ Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'Ontwikkelkracht'.

¹⁰ Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'Eigen kracht'.

¹¹ Original quote in Dutch from focus group interview Wolvega, 28 January 2016: 'Geen cliënt, maar burgers'.

¹² Jeanette, is a person with learning difficulties and worker in a Disabled Person's Organisation (DPO) in The Netherlands.

¹³ The terms 'coach' and 'managers' are given to support people, without learning difficulties, working in the DPO where Jeanette also works.

¹⁴ Harro is a person with learning difficulties working in the same DPO as Jeanette and Henk.

¹⁵ Henk is a person with learning difficulties working in the same DPO as Jeanette and Harro.

Anneke is convinced the state of 'being unknown' restricts opportunity for growth. As such she extended her understanding of *probeerruimte* to encompass the idea of a space of recognition where people are encouraged to try things in the presence of people who are open and accepting. She emphasised the need for:

"An open and accepting space where opportunity is created."

In her analysis of relationships with others, Latimer (2013), makes a distinction between 'alongsideness' and 'being with'. Alongsideness implies being in a proximal position, where connections are intermittent and partial, whereas 'being with' is more encompassing. 'Being with' builds relationships. The art of dwelling amongst different kinds is important for substantiating identities (Latimer, 2013). *Probeerruimte* should facilitate such exposure and in doing so help in the formation of self-identity.

Dwelling among different kinds includes encounters with something or someone other than humans. Latimer (2013) provides rich descriptions of two radically contrasting encounters people can have. One involves animals the other cigarettes. Both encounters demonstrate the opportunity to be alongside a non-human other and enjoy undemanding relations that facilitate pleasurable experiences and connectivity. She describes how these encounters inhabit, invade, move and traverse us and in doing so help to constitute us. These moments of connection, whether it be with an object such as a cigarette or an animal, provide opportunity to order our worlds. Our identities are punctualised by the demands of relations to both human and non-human others. *Probeerruimte* needs to facilitate opportunities for these encounters.

5. Space and Place

The notion of connectivity is related to the concepts of 'space' and *probeerruimte*. Hubbard and Kitchin assert "the articulation of interrelations brings space into being" and they highlight the 'dynamic' nature of space "it is not a neutral container, a blank canvas...filled in by human activity....[It is] inherently caught up in human relations, both socially produced and consumed" (2010, p. 40). Furthermore, place is perceived as a particular 'type' of space, constituted by lived experiences of people, essential for the expression of belonging and the development of identity (Cameron, 2005; Hubbard & Kitchin, 2010; Parr, 2000). Edward Hall asserts place is essential for people with learning difficulties, claiming "people with IDs¹⁶ are more likely to be deprived, to not be in employment, to be in poor health, to be absent from mainstream spaces...and to sense a low valuing of their lives" (2010, p. 48). It is in the mainstream spaces that the myriad of emotions that constitute 'self' (desires, anxieties, passion and love) are able to negotiate 'symbolic geographies of everyday life,' and where people de-

velop prerequisite skills for sustaining self and a relationship with the world (Hubbard & Kitchin, 2010). Inherent to this discourse is the notion of 'liminal space' an 'in-between' space that according to Hjalmarson "is a point more than along the way to somewhere else. It represents anti-structure to structure, chaos to order" (2009, p. 12). Importantly, it is a space where transformation takes place and much of the transformation is due to the removal of control that occurs. Significantly, for people with learning difficulties, 'other people' need to relinquish 'control' as without this the 'self' remains incoherent. Liminal space, almost by definition is a space where self needs to become coherent. Spaces where 'self' is constituted are spaces that render us vulnerable as we negotiate unfamiliar and new territory.

The notion of vulnerability brings us to the critical role that 'risk' plays in regard to *probeerruimte*. It is a space to 'let go' as trust is generated and people can assume 'ownership' for their own actions. Indeed, as alluded to previously, it is a 'risky' place, a positively risky place, where there is a willingness to be vulnerable.

6. Risk Taking

Probeerruimte, and the notion of 'trying' something, entails taking risks (De Ruiter, personal communication, 24 February 2016). Risk taking involves abandoning notions of 'certainty' and beginning to cultivate trust. Trust is a relational concept in contrast to certainty, a more concrete and mechanical concept (Brueggemann, cited in Hjalmarson, 2009). Of importance here is the notion of 'relational autonomy'. Anneke Wignand, observed that *probeerruimte* must also encompass connectivity as it should be a space where networks are established and worlds are widened. Widening of our worlds, and establishing new relationships, inevitably involves taking risks.

Robertson and Collinson identify 'facilitating positive risk taking' as "an essential capacity for health and social care staff" (2011, p. 147). Effectively, it is constructed around managing potential danger by facilitating autonomy and providing positive opportunity for personal growth and development (Robertson & Collinson, 2011). Scholars, exploring the topic of risk, caution against solely negative perceptions of risk and also advise making a distinction between 'risk behaviour' and 'reckless behaviour' (Ravert & Gomez-Scott, 2015). Lupton and Tulloch affirm that "some degree of voluntary risk taking is seen as positive for purposes of personal gain...or self-actualization, or simply as part of the human project" (2002, p. 331). They go further asserting that "risk [is] an inevitable part of everyday life, pervading everything" (2002, p. 325). Integral to decisions about whether or not to take a risk or embrace an opportunity is the central notion of self-determination which is reflected in the fact that individuals make very different choices (Donaldson & Kymlicka, 2011). Risk-taking is suggestive of open spaces where people, who are rendered vulnerable, are

¹⁶ This is a direct quote and IDs refers to Intellectual Disabilities.

able to demonstrate strength and influence. As Budge et al. infer, the ability to exert influence is related to the idea that “people with learning difficulties do not want others determining if they are ‘competent’” (2016, p. 7). As stated before, people with learning difficulties need the opportunity to exercise the same rights as other citizens, including the right to self-determination, thus ensuring their humanity might be recognised.

7. Learning Difficulties, Being Human and the Importance of *Probeerruimte*

For many within disability studies, particularly intellectual disability studies, contestation about the state of being human is related to human rights and specifically citizenship (Cockburn, 2007; Curtice, 2010; Frawley & Bigby, 2011; Jinnah, 2006; Meininger, 2013; Mertens, Sullivan, & Stace, 2006, cited in Laliberte Rudman, 2014; Redley & Weinberg, 2007; Siebers, 2007; Taylor, 2013). Inherent to this line of thought is the idea that being ‘awarded’ citizenship status is one of the ultimate confirmations of being considered human. Some discourse, in this arena, explores the extent to which moral personhood and a ‘life worth living’ can be attributed to people with learning difficulties (Taylor, 2013). Who and what determines a ‘life worth living’?

This question leads us to challenge prevailing ableist ideas that ‘having a disability’ precludes human well-being and agency. This is troublesome and may lead to dire consequences, for instance, denying rights and recognition of personhood to people entitled to citizenship. This is a real concern among people with learning difficulties, who participated in the studies conducted by DSiN, as echoed in the following comment:

“Ik ben ook een mens”—“I am human too.” (Niels¹⁷)

In one of the focus groups an animated discussion about rights to citizenship took place with one member emphatically claiming:

“Imagine if the situation turned around and everyone else became ‘clients’ and we ‘citizens’”? (Harro)

This concern was echoed by another of our participants:

“People with learning difficulties need to be included at all levels, we are all citizens of our countries...We must not be treated as third or fourth rate citizens.” (Robert¹⁸)

Captured in these statements are beliefs that *probeerruimte* needs to be a space where influence is exerted, strength is displayed, rights are claimed, connections occur and self-determination is revealed. These beliefs res-

onate with ideas that were offered when questioned about what it means to be human.

Being human was closely aligned with notions of citizenship, and citizenship has everything to do with affirming rights and membership of a community (Donaldson & Kymlicka, 2015). Importantly, as with the description of *probeerruimte* offered by De Ruiter, eligibility for citizenship is not contingent on linguistic agency or rationality, but rather on being empowered to participate. Understandings of participation need to go beyond exercising individual autonomy and extend to embracing the notion of ‘dependent agency’ where ‘autonomy’ is exercised through the establishment of relationships. This was eloquently described by a participant with learning difficulties in a group interview, when asked about what it meant to be human. With pleasure he described the following:

“Being human has to do with being able to bring pleasure to others. I live close to elderly people and I can see how happy they are when I visit them and offer them help.” (Michiel¹⁹)

Implicit in this description is the idea that ‘being human’ embraces reciprocity and, as with understandings of *probeerruimte*, having the opportunity to exert influence and establish meaningful relationships.

These lines of thought were linked to experiences in institutions and denial of opportunity to ‘think for themselves’. This line of argumentation was offered in support of notions about what it means to be human. Clearly, a strong thread existed between ideas of citizenship, being able to make decisions and feeling human. Perhaps more than for others this notion of citizenship is a contentious issue for people with learning difficulties. Historically, people experiencing learning difficulties have been relegated to the status of second class citizens. This status has usually been attributed to their lack of linguistic skill and lack of reasoning power (DeShong, 2010; Donaldson & Kymlicka, 2011; Goodley & Runswick-Cole, 2014; Latimer, 2013; Siebers, 2007; Wolfe, 2009). Reasoning about citizenship should be turned on its heels. Eligibility for citizenship should not be determined by prerequisite skills such as linguistic ability, rather citizenship should be determined by membership of a society. As Donaldson and Kymlicka assert: “Citizenship is not a prize awarded to those who pass some test of cognitive ‘normalcy’ or linguistic agency, but it is a political status owed to all who are members of a society” (2015, p. 20).

8. Challenging Hegemonic Practices

Power struggles dominated by hegemonic practices drive many of the issues identified in this paper. In their study about the marginalisation of local communities in the

¹⁷ Niels is a person with learning difficulties and works for a DPO similar to the one where Henk, Jeanette and Harro work.

¹⁸ Robert is a person with learning difficulties, the first person with a learning difficulty to address the UN and a NZ ‘People First’ Advocate.

¹⁹ Michiel is a person with learning difficulties and works with the same DPO as Niels.

Great Limpopo Transfrontier Conservation area, Spierenburg, Steenkamp and Wels attest to the impact of power struggles over levels of participation, asserting “communities first have to live up to rigid standards and requirements set by the international conservation authorities, before they are considered ‘fit’ to participate” (2006, p. 18). Some of our participants expressed similar difficulties stemming from the status of ‘client’. As with the local communities Spierenburg et al. (2006) observe, conditional benchmarks and status are clearly determined by hegemonic standards, for instance, rigid standards for cognitive ability, linguistic and reasoning skills. Challenging these standards, the study participants proposed this disempowered ‘client’ status needs to be replaced with the status of citizenship determined by their membership in a shared society, and as citizens, they must be accorded the rights of participation.

In much the same way, prerequisites of autonomy and independence have determined eligibility for citizenship. Discrediting claims for citizenship on these grounds is an issue that resonates with scholars busy with the rights of children and animals (Donaldson & Kymlicka, 2015). Animal theorists, along with disability and child theorists, argue that we need to creatively consider ways to engage the subjectivity of our co-citizens and seek ways to engage their varied ways of existing, including the ways in which we and they connect with others.

Study participants considered the opportunity to connect with others, and specifically to be treated the same as others, a human attribute, inferring the need for access to human rights. As is echoed in the following statement:

“We need to be respected as citizens and have our rights honoured....We need to be more than citizens on paper, you can’t learn to swim from a ‘paper.’” (Harro)

Siebers (2007) affirms this, and asserts that our membership to humanity is highly dependent on a sense of political belonging. Elaborating on this, Siebers draws on Hannah Arendt, highlighting “[the] deprivation of human rights is manifested above all as the deprivation of the status of being human” (2007, p. 1). Within many contexts the right to claim citizenship is contingent on the exercise of certain ‘abilities’ including a minimal knowledge of a language (Benhabib, cited in Siebers, 2007). It is problematic for people with learning difficulties when access to citizenship is determined by certain abilities. The concern is exacerbated when it extends to possibilities for extinction of particular groups that may be deemed unfit for membership of the category human. Arendt drew attention to the circumstances that determine the fragility of eligibility, “a highly organized and mechanized humanity will conclude...for humanity as a whole it would be

better to liquidate certain parts thereof” (cited in Siebers, 2007, p. 3). This concern was echoed by some people in this study:

“Alarm bells are going off...in regard to euthanasia and sterilisation processes....Euthanasia is fine so long as it is a choice made by ‘self’ but there are major concerns that euthanasia decisions are being made for people with disabilities.” (Martin²⁰)

A woman with a physical disability and living in The Netherlands affirmed this concern:

“I think and write a lot about pre-natal testing...because I really feel now we have this negative eugenic....If you look at the Third Reich it was a state decision and now it is a personal decision....We make the mistake of thinking if it is a personal decision it is good, that it is a free decision, but that is a mistake....The effect is the same, it is exactly the same as in the Third Reich.” (Marie-Jose²¹)

These concerns were unequivocally linked to perceptions of what it is to be human:

“People with intellectual disability have been a deeply oppressed group of our society, they have been the butt of eugenic policies...and I think the Euthanasia law...in The Netherlands is incredibly dangerous for disabled people....One reason is that their voices have to be heard....You know you have to turn around this view that they are not real humans....It is only in hearing their voices that their humanity will be seen and recognised.” (Martin)

Inherent here is a desire to impose order. Imposing order is closely related to the practice of ‘othering’. Of particular concern for disability studies are the mechanics of ‘othering’ and the practice of making comparisons to prove exceptionalism. This is dangerous ground as comparisons tend to work negatively in order to degrade the other (Latimer, 2013). The practice of ‘othering’ has engendered in humans a stance that is oppositional and aggressive leading to exclusive practices and at times violent exclusions (Latimer, 2013). *Probeerruimte*, offers a space where recognition of a person’s ‘humanness’ can occur.

Posthumanist theories make an appreciable counter to the arguments offered above, challenging the ease with which distinctions are made between ‘human’ and ‘non-human’ categories (Goodley & Runswick-Cole, 2016; Haraway, 1991; Latimer, 2013; Reeve, 2012). Linking this to disability, Goodley et al., assert, “Critical disability studies...are perfectly at ease with the posthuman because disability has always contravened the tra-

²⁰ Martin has a spinal injury and uses a wheelchair. He is a Senior Lecturer in the School of Social Work at Massey University, NZ where his specialist area of teaching is Disability Studies and Social Policy.

²¹ Marie-Jose is a Gestalt therapist and writer in the field of disability, illness and medical ethics. She has a progressive muscle disease.

ditional humanist conception of what it means to be human" (2014, p. 342). The ease with which critical disability studies embraces posthumanism, and inadvertently perceives 'human as a contested concept', is related to the discomfort disability studies has with conceptions of 'humanity'. This discomfort has been fed by unease with eighteenth and nineteenth-century classical portrayals of humanity, and more recently, based on modernist and capitalist hegemonic constructions ascribing the status of 'human' only to white, masculine, urbanized, heterosexual citizens, 'speaking a standard language' (Goodley et al., 2014). They further assert, in contexts that weave capital, technologies, and communication through real and virtual spaces, the ideal of a rational, independent, solitary and able-bodied human subject is rendered unrealistic, if not fictional (Goodley et al., 2014).

9. Conclusion

This paper has juxtaposed the Dutch term *probeerruimte* and the statement 'human as a contested concept' exploring the term and searching for its relevance to notions of being human. *Probeerruimte*, as conceived by its author, De Ruiter, is a space where people who are usually subject to institutionalised and restrictive rules and regulations, are able to try out new things and, in doing so, are able to develop as human beings. He points out an important aspect of 'trying' is the exertion of influence. 'Exerting influence' presupposes a relational context where one can exert influence over another and manipulate situations in a desired manner. Inherent to a relational context is the notion of connectivity which, for some participants contributing to this paper, was significant for *probeerruimte*. The term was portrayed as a place where it is important to know and be known, to be recognised. The relational aspect of *probeerruimte* linked significantly to understandings of what it means to be human, where establishing relationships is pivotal.

For some people with learning difficulties, whom we interviewed, denial of what has been conceived of as *probeerruimte* is akin to denying their human rights and status as citizens. Eligibility for citizenship is central to understandings of what it means to be human and a number of our participants were emphatic that being awarded the status of citizenship ensures they have the same rights as others. Instances of the troubles 'marginalised' people have in claiming citizenship, drew attention to restrictive hegemonic practices that establish rigid exclusionary standards. Citizenship should not be contingent on linguistic skills or rationality, rather, by virtue of membership to a society, citizenship it should be accorded as a right. Although the complex topic 'inclusive citizenship' (Curtice, 2010) is clearly beyond the scope of this paper, we want to reiterate the huge significance of this broader issue for further contextualisation and conceptualisation of *probeerruimte*.

Acknowledgements

The authors would like to thank the two anonymous reviewers of this paper for their helpful and constructive comments. We are grateful to Disability Studies in Nederland (DSiN) for the opportunity to be involved in this research project. We want to extend a special thanks to people living with learning difficulties and working for the disability organisation, LFB, in Utrecht and Wolvega in The Netherlands, and former Inclusion International Council member, Robert Martin in New Zealand, who so willingly shared their knowledge and experiences in regard to their perceptions of what it means to be human. We are of course particularly grateful to Willem de Ruiter, the author of the term '*probeerruimte*' who readily and extensively shared his expertise about this concept. Martin Sullivan we are extremely grateful for your elaborative insights. We are also thankful for the contributions of Marie-Jose and Aneke Wignand and your wise understandings of this topic. Dr Michiel Vermaak, thank you for drawing attention to the need to explore this concept more closely. Last but not least, thanks to Maureen Crawford, for her meticulous proofreading skills.

Conflict of Interests

The authors declare no conflict of interests.

References

- Bourke, J. (2013) *What it means to be human: Historical reflections from the 1800s to the Present*. Berkeley: Counterpoint.
- Budge, F., Ebben, H., & Van Hove, G. (2015). *Nationaal Programma Gehandicaptenzorg (werkpakket C: coöperatief/participatief ontwikkelen en onderzoeken)*. Amsterdam: VU, Metamedica.
- Budge, F., Schippers, A., Kool, J., Miranda-Galarza, B., & Van Hove, G. (2016). More than a 'nice day out': How to encourage the meaningful participation of people with learning difficulties in disability conferences. *Sky Journal of Educational Research*, 4(3), 27–34.
- Cameron, A. (2005) Geographies of welfare and exclusion: Initial report. *Progress in Human Geography*, 29, 194–20
- Cockburn, T. (2007). Partners in power: A radically pluralistic form of participative democracy for children and young people. *Children & Society*, 21, 446–457.
- Curtice, L. (2010). *Lessons for inclusive citizenship? Difference, disability and rights in the lives of people with learning disabilities who have high support needs* (PhD Thesis). University of Glasgow.
- DeShong, S. (2010). Ability and the Human. *PMLA*, 125(3), 816–817.
- Donaldson, S., & Kymlicka, W. (2011). *Zoopolis: A political theory of animal rights*. Oxford: Oxford University Press.
- Donaldson, S., & Kymlicka, W. (2015). Rethinking mem-

- bership and participation in an inclusive democracy: Cognitive disability, children, animals. In *Disability and political theory*. Cambridge: Cambridge University Press.
- European Intellectual Disability Research Network. (2003). *Intellectual disability in Europe* (working papers).
- Foucault, M., Bertani, M., Fontana, A., Ewald, F., & Macey, D. (2003). *"Society must be defended": Lectures at the Collège de France, 1975–1976* (Vol. 1). London: Macmillan.
- Frawley, P., & Bigby, C. (2011). Inclusion in political and public life: The experiences of people with intellectual disability on government disability advisory bodies in Australia. *Journal of Intellectual & Developmental Disability, 36*, 27–38.
- Goodley, D., Lawthom, R., & Runswick-Cole, K. (2014). Posthuman disability studies. *Subjectivity, 7*(4), 342–361.
- Goodley, D., Runswick-Cole, K., & Liddiard, K. (2015). The dishuman child. *Discourse: Studies in the Cultural Politics of Education, 37*(5), 770–784.
- Goodley, D., & Runswick-Cole, K. (2016). Becoming dishuman: Thinking about the human through dis/ability. *Discourse: Studies in the Cultural Politics of Education, 37*(1), 1–15.
- Green, J., & Thorogood, N. (2013). *Qualitative methods for health research*. London and New Delhi: Sage.
- Hall, E. (2010). Spaces of social inclusion and belonging for people with intellectual disabilities. *Journal of Intellectual Disability Research, 54*(s1), 48–57.
- Hall, E., & Kearns, R. (2001). Making space for the 'intellectual' in geographies of disability. *Health & Place, 7*(3), 237–246.
- Haraway, D. (1991). *Simians, cyborgs, and women: The reinvention of nature*. New York: Routledge.
- Hjalmarson, L. (2009). Forty years in a narrow space. *Stimulus: The New Zealand Journal of Christian Thought and Practice, 17*(3), 12–17.
- Hubbard, P., & Kitchin, R. (Eds.). (2010). *Key thinkers on space and place*. Los Angeles, London, New Delhi, Singapore and Washington, DC: Sage.
- Jinnah, S. (2006). *Sustaining services and support for individuals with disabilities and their families* (BA Thesis). University of Victoria.
- Kittay, E. F., & Carlson, L. (Eds.). (2010). *Cognitive disability and its challenge to moral philosophy*. New York: John Wiley & Sons.
- Laliberte Rudman, D. (2014). Embracing and enacting an 'occupational imagination': Occupational science as transformative. *Journal of Occupational Science, 21*(4), 373–388.
- Latimer, J. (2013). Being alongside: Rethinking relations amongst different kinds. *Theory Culture & Society, 30*(7/8), 77–104.
- Lupton, D., & Tulloch, J. (2002). "Risk is part of your life": Risk epistemologies among a group of Australians. *Sociology, 36*(2), 317–334.
- Meininger, H. (2013). Inclusion as heterotopia: Spaces of encounter between people with and without intellectual disability. *Journal of Social Inclusion, 4*(1), 24–44.
- Parr, H. (2000). Interpreting the 'hidden social geographies' of mental health: Ethnographies of inclusion and exclusion in semi-institutional places. *Health & Place, 6*(3), 225–237.
- Rabiee, F. (2004). Focus-group interview and data analysis. *Proceedings of the Nutrition Society, 63*, 655–660.
- Ravert, R. D., & Gomez-Scott, J. (2015). Why take risks? Four good reasons according to emerging adult college students. *Journal of Adolescent Research, 30*(5), 565–585.
- Redley, M., & Weinberg, D. (2007). Learning disability and the limits of liberal citizenship: Interactional impediments to political empowerment. *Sociology of Health & Illness, 29*(5), 767–786.
- Reeve, D. (2012). Cyborgs, cripples and iCrip: Reflections on the contribution of Haraway to disability studies. In D. Goodley, B. Hughes, & L. J. Davis (Eds.), *Disability and social theory: New developments and directions* (pp. 91–111). London: Palgrave Macmillan.
- Robertson, J. P., & Collinson, C. (2011). Positive risk taking: Whose risk is it? An exploration in community outreach teams in adult mental health and learning disability services. *Health, Risk & Society, 13*(2), 147–164.
- Rose, N. (2007). *The politics of life itself*. Princeton and Oxford: Princeton University Press.
- Schoonheim, J., & Smit, J. (2007). *Report on the social inclusion and social protection of disabled people in European countries*. Leeds: Academic Network of European Disability Experts.
- Siebers, T. (2007). Disability and the right to have rights. *Disability Studies Quarterly, 27*(1), 19.
- Smits, J. (2012). *Violations of human rights of people with disabilities in the Netherlands*. Retrieved from <http://www.netwerkperspectief.nl/actueel/2012samenvattingupr.pdf>
- Spierenburg, M., Steenkamp, C., & Wels, H. (2006). Resistance of local communities against marginalization in the Great Limpopo Transfrontier Conservation Area. *Focaal, 2006*(47), 18–31.
- Taylor, A. (2013). "Lives worth living:" Theorizing moral status and expressions of human life. *Disability Studies Quarterly, 33*(4).
- Thomas, C. (2007). *Sociologies of disability and illness: Contested ideas in disability studies and medical sociology*. New York: Palgrave Macmillan.
- Townsley, R., Ward, L., Abbott, D., & Williams, V. (2009). *Academic Network of European Disability experts* (ANED): VT/2007/005. Bristol: ANED.
- Wolfe, C. (2009). Human, all too human: "Animal studies" and the humanities. *PMLA, 124*(2), 564–575.

About the Authors



Fiona MacLeod Budge has a background in Occupational Therapy and Medical Anthropology, her research and academic publications have mainly focused on the value of inclusive and participatory approaches in both disability studies and health promotion efforts. She has her own communication and advocacy consultancy and frequently delivers training to people working with so-called 'marginalised groups'. The most recent course focuses on developing research and advocacy skills of disabled people.



Harry Wels was trained as an anthropologist. His research and academic publications have mainly focused on organisational and management processes in (private) wildlife conservation in South and southern Africa. Since his 'animal turn' a couple of years ago now, he tries to include the 'non-human other' in his fieldwork and in interpreting human-animal configurations in wildlife conservation. Rethinking what it means to be human in this context has been an enduring intellectual challenge for him.